



Equality Community Insights

Insights from 3 LGBTQ+ organisations

May 2023

Introduction

Equality is a community engagement agency that addresses health inequalities by improving inclusion in health research. Our mission is to increase the representation of under-served groups in health research so that healthcare and treatments are accessible and effective for all.

To achieve this aim, we are working with the queer community to increase their representation in research. As a first step, we ran a focus group in October 2022 to listen to their experiences of taking part in health research and engaging with the health sector.

This report is a summary of that discussion. It sets out key themes from the experiences that were shared, and recommendations to improve practice.

This is the first step in Equality's journey of working with the queer community. We look forward to working more closely with the community to deepen our knowledge and build partnerships with the health research sector to improve practice.

Methodology

In October 2022 Equality held a focus group with grassroots organisations that work with the LGBTQ+ community across the UK.

The Focus Group was attended by 14 members from three different organisations: [Bahagari UK](#), [LGBT Health and Wellbeing UK](#), and [Notts LGBT](#). The aims of the focus group are set out below:

- Gain an understanding of the inequalities and challenges the community faces when engaging with the health research and life sciences sector
- Listen to what the LGBTQ+ community wants from the health research and life sciences sector, and how the community can benefit from it
- Establish how Equality can better aid the LGBTQ+ community in health research to ensure LGBTQ+ people are respected and represented in clinical trials/health research

Overview

The focus group discussion gave us critical insights into the past experiences of LGBTQ+ individuals taking part in health research and their engagement with the health sector. We heard that the community at large is willing and eager to participate in research, but a trend of poor past experiences has resulted in mistrust toward researchers, research objectives, and the research process.

The experiences participants shared highlighted poor practice among healthcare professionals and researchers, leading to negative experiences and potentially triggering past trauma for LGBTQ+ individuals.

Mistrust toward the sector largely relates to not knowing how potential participants will be treated by researchers and the overwhelming worry that they will face experiences where their identities are invalidated. This mistrust is rooted in the shared experiences of the LGBTQ+ community in and outside of health research. Which means individuals are hesitant about participating, even if they have not taken part in health research before.

When looking at experiences specific to the trans community, past experiences have been marred due to healthcare professionals invalidating their identities or not understanding their specific health needs. Trans individuals who continually engage with the healthcare sector for medical, therapeutic, and hormonal support can often feel unsafe and excluded, which furthers community-wide mistrust.

The backdrop of national conversations on queer-exclusionary policies, lack of funding, and the government's weak stance on trans healthcare as well as the community's well-being furthers the negative experiences of LGBTQ+ individuals and makes them hesitant to actively engage with health researchers and clinical trials. There are several studies, referenced at the end of this report, that document the health inequalities faced by the queer community, and the politics associated with it. A 2019 [Sessions Report](#) by the Women and Equalities Committee of the UK Parliament's House of Commons summarised the issue:

“LGBT people need to be treated equally, but not identically to, other groups. Access to the same services as others is ineffective if that service is structured for a heterosexual and cisgender default and has limited flexibility. There is not enough understanding from service providers of the different needs that LGBT people might have.”

Key themes from discussions

I. Understanding LGBTQ+ identities and sharing information appropriately

Overview

Many healthcare professionals and researchers do not understand the spectrum of LGBTQ+ gender and sexual identities.

Example

A local hospital's mail communication with a trans woman reflects the lack of understanding of varying gender & sex identities within the healthcare system. As part of the communication on cervical cancer screening, the hospital had misidentified the individual as a (cis) woman and not as a trans woman. Apart from the highly negative experience of being misgendered by a healthcare professional, this speaks to a larger issue of understanding identities and information sharing. This type of experience could have severe ramifications for the trans population at large. For example, trans men who might be eligible for cervical cancer screenings may be entirely excluded from related communications and awareness campaigns, thereby increasing the risk of delayed diagnoses and healthcare issues.

Conclusion

This lack of understanding and appropriate information sharing can be an extremely negative experience for queer individuals, and can impact their mental and physical health. Consequently, these experiences in the health system can affect people's willingness to be involved in research. There is also a broader question in research about how sex and gender identities are appropriately recorded and shared. Equality will be exploring this further in upcoming focus groups.

II. Communicating why we need LGBTQ+ people represented in research

Overview

Researchers do not explain the need for diverse representation in research to members of the community, which leads to people feeling tokenised, that is, reduced solely to their gender and sex identities for the sake of fulfilling a quota.

Example

In instances where there was little to no communication regarding the broad research goals, aims and objectives of the study, and the role of participants in helping the researchers fulfil their objectives, participants felt isolated and reduced to mere statistics that help make the study "diverse" and valid. There also seemed to be a lack of understanding within the research community on why LGBTQ+ participants were integral to a study and how they contributed to the research.

Conclusion

Integrating participants into a research study by demonstrating how their inputs are critical to the project's objectives and success is an essential component of conducting research that is representative, diverse, and inclusive. For LGBTQ+ individuals, when paired with numerous other negative experiences, a lack of affirming and consistent communication can signal ignorance, tokenism, and disregard of their identities by the researchers.

This furthers the exclusion of LGBTQ+ experiences and voices from healthcare research, reinforcing a negative cycle where poor experiences cause withdrawal from research, which leads to studies that are not inclusive of all identities.

III. Communicating consistently before, during, and after the study

Overview

Researchers do not communicate adequately with participants throughout the research, leading to feelings of isolation and being used.

Example

One of the participants in the focus group recalled being part of a project where they were asked to give bio-samples. However, upon the cancellation of the project, there was no communication regarding the samples and management of confidential information. These experiences have a negative impact by reducing people's trust in the research process and furthering scepticism about the sector. Especially with research that involves taking samples from the participants, it is crucial to share data management and confidential information handling procedures before and during the research.

Conclusion

Lack of adequate communication throughout the research process can often make participants feel isolated or ignored. Communication, when done consistently and in a manner that reinforces the integral nature of participants to the research objectives, can lead to positive experiences and the building of trust with the system at large.

Conclusion and recommendations

- Improve the representation of the LGBTQ+ community in healthcare staff and research
- Provide sensitisation and awareness training for healthcare professionals and researchers to equip them with better ways of communication, working, and good practices
- Provide full disclosure of the need to record gender and sex information, its relevance, and purpose on medical documents, forms, or in research
- Keep administrative documents and forms up to date with inclusive terminology and data fields (e.g., using 'sex assigned at birth' instead of 'sex' or 'biological sex', giving an option to self-describe gender)
- Display solidarity and support toward the LGBTQ+ community, especially in times of rising intolerance and anti-queer rhetoric



Contact Us

If you'd like to know more about our work or partner with us to improve inclusion and diversity in health research, please reach out at team@equality.health

